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ABSTRACT

Presented is a report on the California Governor's Conference of December, 1973, called to assess knowledge of preventive techniques in the field of developmental disabilities and to develop a more extensive design for future action. Keynote addresses by F. Lanterman and E. Brian are quoted. Summaries of the following talks are included: Prevention of Developmental Disabilities -- the Pre-conception Period (M. Golbus); The Prevention of Mental Retardation and Genetic Disease -- Early Pregnancy (A. Milunsky); Prevention of Developmental Disabilities in Later Pregnancy and Delivery (A. Parmelee and C. Kopp); and the Infant and Young Child (J. Meier). Examined in the document are eight recommendations representing a composite of the 91 recommendations proposed by the more than 200 persons attending the conference. The recommendations noted include the following: provide education and information pertaining to the prevention of developmental disabilities to all Californians and, in particular, to adolescents, prospective parents, and all practicing professionals; coordinate and, where necessary, expand services to prospective parents, expectant mothers, newborns, and their parents, so as to provide comprehensive and continuous coverage from pre-conception through delivery and early infancy; and review and assess the preventive services provided through regional centers and critically assess their capacity to undertake a full range of preventive programs. Names and addresses of the conference participants are listed. (IM)

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Tomorrow Is . . .

REPORT ON
THE GOVERNOR'S CONFERENCE
ON
PREVENTION OF
DEVELOPMENTAL DISABILITIES

HELD AT

NEWPORT BEACH, CALIFORNIA
DECEMBER 2 – 4, 1973

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FOREWORD

The Governor's Conference on Prevention of Developmental Disabilities was called expressly to assess existing knowledge of preventive techniques and to develop a more extensive design for action in the future.

Those attending the conference took a close look at ways of dealing with the problems of developmental disabilities, not only prior to and after childbirth, but before conception as well.

Two full days of intense deliberations by 200 physicians, nurses, health specialists, educators, social workers and parents provided 91 recommendations to prevent or minimize the effects of developmental disabilities. The most frequently mentioned recommendations have been combined into eight key recommendations which appear in this report.

It is hoped that these recommendations will help reduce the loss of human as well as fiscal resources and ease the psychological drain experienced by family members.

All attempts will be made to implement the recommendations as quickly as possible.

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MESSAGE FROM THE GOVERNOR

by

Hon. Ronald Reagan, Governor
State of California

I would like to welcome each of you to this conference on prevention of disabling conditions which lead to mental retardation, cerebral palsy, epilepsy and other neurological handicaps.

I have called this important conference expressly for the purpose of dealing with the problems of developmental disabilities prior to their onset rather than after they occur. I believe this is a priority subject for California and the nation.

California is committed philosophically and morally to providing the highest quality of service at locations most appropriate to the needs of its developmentally disabled citizens. Prevention services should be an integral part of these services in each community.

Over the past decade, tremendous growth and knowledge has taken place in the fields of child and human development, biochemical genetics, and most recently in immunology. This should enable us to establish preventive practices which will reduce the financial and emotional impact that accompanies the birth of a severely disabled child.

To my knowledge, California is the first state to call such a conference. I believe this is most fitting against the backdrop of what California has been doing during the last decade. For example, we began the regional centers for the mentally retarded in the middle sixties, with one in the north and one in the south. These existed for several years while we developed the system that became the foundation for current programs. This was a *first* in establishing a delivery system of coordinated services.

Out of this experience came the Mental Retardation Services Act of 1969, authored by Assemblyman Frank Lanterman. As a result of this landmark legislation, there is now a network of 16 regional centers throughout the state. More are planned. This means it is now possible to purchase the necessary services to meet the total needs of the mentally retarded wherever they may be located in California.

Since our pioneering efforts, the federal government has taken a positive position resulting in financial support for services not only for the mentally retarded but for cerebral palsy, epilepsy and other neurologically handicapping conditions that occur before the age of 18. Through subsequent legislation, which I signed this year, our regional centers now will be serving California citizens with all developmental disabilities.

Under the original Lanterman Mental Retardation Services Act, 13 Area Mental Retardation Planning Boards were established. This allows meaningful input from the grass-root level on the needs of disabled persons. These 13 area boards present an area plan stating their needs to the state via the Developmental Disabilities Planning and Advisory Council. No longer is the state forced to make decisions in Sacramento without knowledge of the real needs of local communities.

In the field of education, the state has developed a wide spectrum of services ranging from a mandated system for trainable and educable children from kindergarten through high school. As an alternative to hospital placement, we have expanded and are continuing to expand development centers for the handicapped. They accommodate those from 3 to 21 years who do not qualify for school programs. Children in these development centers frequently move into regular school settings, and the development center network grows each year.

Our goal is that no handicapped person will wait for services that he needs near his home. Classes and services also are being developed for other handicaps within the framework of the Department of Education. Crippled children's services also offer specific programs for the crippled child through maternal and child health.

Community colleges, state college universities, and the University of California system are also actively pursuing manpower training programs to meet the needs for trained personnel as services and programs develop. Without qualified and trained personnel, new programs cannot become a reality.

Much remains to be done. Recognizing this fact, we have attempted to eliminate fragmentation of services by establishing a state Department of Health. Education is refining their master plan for special education in order that we might sharpen our existing service programs.

Our goal now is to work toward the total elimination of the problem of developmental disabilities. You are here because all of the necessary resources have not been mobilized at this time.

The design of this conference is for *action*. With the tremendous talent assembled here, I am sure that constructive and realistic solutions will be forthcoming. I await not only your suggestions, but your plans and methods for accomplishing this task. Our goal is to reduce and eliminate the problems of developmental disabilities.

KEYNOTE ADDRESS

by

The Hon. Frank Lanterman

California State Assembly

I want to take this opportunity to commend Governor Reagan for establishing this Conference on Prevention of Developmental Disabilities and to express my appreciation to Juanita Shaffer, Al Toedter, and Dr. John Morris for their many hours of hard work in planning this most important conference. I would also like to thank my distinguished friend Chancellor Dan Aldrich for being our local host here in Orange County.

During the past several years we have made great progress in improving and expanding *service* programs for the developmentally disabled.

- The Regional Center Program has grown from 2 Centers in 1966 to 15 Centers in 1973.
- During this same period the Regional Centers caseload has increased from serving 200 families in 1966 to over 10,000 at the present time.
- And the Regional Center Budget has grown from $575,000 to $27 million during the past seven years. This $27 million includes a $5 million budget augmentation this year which was requested by Earl Brian and his staff.
- As a result of the passage of my AB 1759, we will have 20 Regional Centers with a budget approaching $50 million by 1975.
- Educational services have also expanded in the last several years.
- We have more EMR (Educable Mentally Retarded) and TMR (Trainable Mentally Retarded) classes. We have expanded the number of Development Centers, and Sedwich Act funding has allowed many private institutions to provide acutely needed educational programs.
- State hospital Services for the developmentally disabled have also dramatically improved. Staffing ratios have been enriched, overcrowding has been virtually eliminated and many new programs have been initiated.

I have listed very briefly some of the major developments in terms of *services* for the developmentally disabled.

Now I would like to turn your attention to the primary subject of this conference – prevention of developmental disabilities.

Just as service programs have grown in the last several years, so has our knowledge of preventive techniques.

The revolution in biology, which started in the forties has grown at a rapid pace in the last decade. By the 1960's advances in biochemical genetics led to new knowledge concerning inborn errors of metabolism; cytogenetics has led to a new

understanding of a large variety of abnormalities; and more recently the developments in imunology have enabled us to make significant contributions to preventive practices.

I think it is particularly important to note that in spite of this increase in knowledge, we are spending a disproportionately small sum on implementing knowr preventive techniques.

For example, of the $301 million contained in the developmental disabilities budget for 1973-74 only $746,000 was earmarked for preventive activities. This amounted to less than 1/3 of 1%.

In partial recognition of this problem, the Legislative Conference Committee on the Budget, of which I am a member, augmented the Budget by $500,000 for additional genetic counseling services including funding for a sickle cell anemia screening project in Northern California and a Tay Sachs project in Southern California.

But obviously there is much more that needs to be done. As a starting point I would urge this Conference to carefully review the proposals made by Art Bolton and Valerie Bradley in "A Report to the State Assembly on Developmental Disabilities in California" which was published in April, 1972.

Part II of this report included many far-reaching and innovative suggestions in the areas of prevention and early intervention.

Specifically the report recommends:

1. Establishment of a statewide reporting system and central registry for mothers and infants "at-risk" to assure that children born with handicaps or at risk of developing handicaps receive special attention.
2. Establishment of comprehensive prenatal and infant care pilot projects in selected "target areas" of the State.
3. Expanded care finding and public education activities.
4. Increased dietary and nutrition counseling services.
5. Expanded comprehensive family planning services and counseling.
6. Improved pregnancy testing and early identification of mothers at risk of premature deliveries.
7. Establishment of regional intensive care units throughout the state to care for the seriously distressed infant.
8. Development of improved emergency infant transportation systems to assure access to intensive care units.
9. Development of new standards to upgrade general maternity care and delivery procedures for *all* of the State's public and private hospitals.
10. Establishment of high-risk birth certificate follow-up procedures.
11. Expansion of infant stimulation programs in organized settings.
12. Home visits by public health nurses to families with developmentally disabled children.
13. Establishment of services which would facilitate the delivery of preventive services such as baby-sitting, homemaker services, and public service announcements.

Although the Bolton Report was presented to the Legislature 1½ years ago, few of the recommendations have actually been implemented. The State of Illinois has reviewed this same report and has taken steps to implement all its major provisions.

In terms of the work of this Conference, I would suggest that the Bolton Report may provide a good starting point from which you can add many other innovative ideas and proposals.

In summary, it is clear that the costs of treating the developmentally disabled are tremendous, particularly when we consider the loss of human potential and the continuous drain on family resources – both financial and psychological.

It is true that many of our adult developmentally disabled were born at a time when medical technology was unable to fully cope with their problems. But it is also true that during the past several years the state of the art of preventive techniques has been greatly improved and continues to progress at a rapid rate.

The costs resulting from our comparative neglect of funding preventive work will continue to burden the State for the next generation unless the cycle is stopped through increased availability of resources and implementation of the technology which already exists.

We have gained a great deal of knowledge and experience, and I think the main purpose of this Conference is to assess what we have learned and to develop a road-map for the directions we should be moving in the future. While we have a rich history on which to build, none of us yet know all of the solutions to these problems. But as James Thurber cogently put it, "It's better to know *some* of the questions than *all* of the answers."

KEYNOTE ADDRESS

by

Earl Brian, M.D.

Secretary, Health and Welfare Agency

I have given over a good portion of the past year to moving about the state, meeting with many of the Health and Welfare Agency's 45,000 employees, as well as meeting with organizations and individuals whose activity and interest are in concert with agency programs.

Those travels have carried me to nearly all of the state hospitals and several regional centers – and I have been able to see first hand the kinds of care and treatment that mark California's programs – making them unique and placing them at the very top of the nation's finest efforts for the developmentally disabled.

Any of you who have shared in seeing those activities and those facilities could not have helped coming away with much the same thoughts the experience produced for me.

And that is, so much of this need should never have been.

In an era of almost daily scientific and medical miracles, these disabled individuals represent more than the wonderful care and treatment which will enable them to take an optimal place in sharing our life – it also clearly represents a terrible waste of human potential, particularly in the face of so many advances in other fields which have alleviated or eliminated debilitating disease and other forms of human affliction and suffering.

California has upwards of 180,000 people who are developmentally disabled and getting some form of help from our statewide programs. An impressive number, most certainly.

But that number points up a concern that brings us here today, a concern that not only must we strive to improve care and treatment for them – but also move swiftly in finding ways to insure that those to follow in years to come will diminish in number – that detection and prevention programs will take the lead and priority so long overdue.

True, much has been done toward that end. The field has crossed the threshold of major change and advance.

Some ways to foster growth and learning in even the most severely disabled have been found. The secrets of the human cell's programming for the unborn have been pried out.

The most critical years to impart learning have been found to be far before the time when formal education would normally begin.

Developing successful instruction for the developmentally disabled has enabled us to find steps in the learning process previously unknown and even unsuspected.

In many ways, we are finding that we have just tapped the potential to be found and enhanced for the developmentally disabled. Yet, I believe that we are all aware of the roadblocks to making these discoveries and the many that remain to unfold – as well as putting into action that which we already know.

In our characteristic pell-mell rush to do the job well in all areas of concern, we have also characteristically created a vast array of fragmented delivery, waste and inefficiency.

We have already made inroads in this state to move away from those factors and improve that situation. Significant to that end within recent months has been the organization of the new State Department of Health – a move calculated to make current programs more responsive and more coordinated in their service to Californians in need.

Additionally, the entire planning process for the developmentally disabled has been realigned to produce a meaningful working plan for our regional centers.

These and other actions form just a part of the solution – and admittedly have far to go in that spectrum of activity in order to function well in the ultimate delivery of care. But the fact remains that we have come very, very far in a relatively short time.

Much remains to be done – and that is what brings us to this gathering today.

We all share in the expectation of the action to come out of this new beginning – a plan which will serve well for many years in the bringing together and blending of all the resources, all of the knowledge, all of the programs and all of the diverse individual efforts now at hand in California.

It is an awesome task, but clearly one that must be accomplished if we are to move toward achieving a national goal of reducing by one-third the incident of developmental disabilities by the end of this century – a mere 27 years away.

I personally believe that we have or will have the expertise and resources to achieve that goal much sooner and in fact, can, and will – eliminate totally the causes of this tragic waste.

Your being here today places you in the vanguard of an effort to move toward that end – an end that will set a pattern which will eventually be emulated nationally, as so many California innovations have been.

Your involvement and the subsequent production of a plan will show others how to better put to use the best knowledge available on prevention. It will show others how to best mobilize the many organizations and agencies to produce focused programs at both the primary and secondary prevention levels.

In just a few moments, you will be hearing about the areas to which your actions will be addressed: *The Preconception Period; Early Pregnancy; Later Pregnancy and Delivery;* and *The Infant and Young Child.*

In dealing with those four areas, I would strongly urge you to think and translate all facts into goals and objectives – for the conference you are attending here today is not just another conference – the action plan you will ultimately produce is not just another plan.

It is, in fact, the kind of plan which will have far-reaching impact for years to come, and for that reason, I give you my commitment that, insofar as I am able, this

plan, *your* plan, will have all the appropriate resources and manpower now under the Health and Welfare Agency brought to bear on the task you set out.

This is just the beginning of many years of effort toward a goal of unquestionable merit, and I believe you should be mindful that what you do will insure:

- That someday mental retardation, cerebral palsy, epilepsy and the many other causes of developmental disabilities will be nothing but a bitter memory.
- That someday parents will not have to live in fear of a question that has haunted them since the beginning of mankind.

So what you do here today is not merely a challenge from a personal or professional point of view — it is also part and parcel of the spirit of reaching out to help others. That spirit is the backbone of this state and this nation — and it is as old as America itself.

PREVENTION OF DEVELOPMENTAL DISABILITIES
THE PRE-CONCEPTION PERIOD

by

Mitchell S. Golbus, M.D.

Any discussion of the prevention of developmental disabilities requires that the causes of such disabilities first be identified. To make this task more manageable the organizers of this conference have elected to look at this problem chronologically. They realized the prevention of developmental disabilities starts in the pre-conception period or inter-pregnancy period and our discussion starts here. There are three major areas I'd like to have you consider. They are: (1) genetic influences, (2) parental health status, and (3) nutritional influences.

The significance of genetic influence is stressed by the fact that 42% of pediatric deaths have an underlying genetic cause. The genetic influence on developmental disabilities takes many forms. The action of single genes inherited from each parent in an autosomal recessive manner is seen in those children born with inborn errors of metabolism. These include the storage diseases, such as Hurler's syndrome, which cause a severe degree of mental retardation. Conditions inherited in a polygenic manner are exemplified in children born with spina bifida or meningomyelocele – conditions now amenable to prenatal diagnosis by determination of the amniotic fluid level of α-fetoprotein.

The importance of parental age and its influence on developmental disabilities should also be recognized. The relationship of increased maternal age and the increased incidence of offspring with Down's syndrome is well known, but less well known is the fact that children born to adolescent mothers have an increased incidence of anatomic malformations. Paternal age is a numerically less important, albeit real, influence as seen in the relationship between increased paternal age and the incidence of a number of conditions inherited in an autosomal dominant manner.

Although the genetic constitution of potential parents is currently unalterable there are a number of possible projects that could influence the incidence of developmental disabilities with a genetic etiology. Erythroblastosis fetalis secondary to Rh incompatibility is an example of a genetically determined condition that has been virtually eliminated by medical advances. The provision of genetic counseling and prenatal diagnosis services throughout the state would lower the incidence of children born with developmental disabilities. Furthermore, identification of carriers of autosomal recessive conditions causing severe disability before they produce children with such disease states, coupled with adequate counseling, could eliminate many such tragic births.

For the sake of simplifying discussion, I will divide parental health status into (1) maternal biomedical health, (2) parental psychological health, and (3) parental socioeconomic health. It must be emphasized that these are in reality interrelated factors and are not separable when dealing with individuals. Examples of the pre-conception influence of maternal health status are provided by women afflicted with diabetes mellitus or with hypertensive vascular disease. There is evidence that the fetal and perinatal problems of the progeny of diabetic mothers are related to the existence of maternal vascular complications. These vascular complications may be related to the pre-conception control of the diabetic state and by the time of conception much of the outcome of the pregnancy may have been pre-determined. The significance of hypertensive vascular disease is related to its correlation with intra-uterine growth retardation. Among infants with IUGR, 1% have cerebral palsy, 6% have convulsions, 25% have minimal cerebral dysfunction, and 64% have EEG abnormalities.

The second category, that of parental psychological health, is concerned with whether potential parents are emotionally prepared for parenthood. Do they know what being a parent involves? Do they know what normal development is? Would they recognize a developmental disability in their own children?

The third component of parental health status, that of socioeconomic health, is perhaps the most nebulous area, but may be the most important. The vast majority of developmentally disabled children are only minimally disabled and have no known etiology to their disability. Many of these children come from a social situation where there is a virtual absence of intellectual stimulation. An improvement in the socioeconomic health of parents might be the greatest single step in reducing incidence of developmental disabilities.

The last major area I wish to call to your attention is that of nutritional influence on developmental disabilities. There is evidence that inadequate nutrition can contribute to intra-uterine growth retardation and its subsequent disabilities. The collaborative obstetrics study has found that a woman's pre-conception weight is directly related to the birth weight of their offspring. Women with a pre-conception weight under 100 pounds had a significantly increased risk of having a small-for-date infant. We also must recognize that the adolescent pregnancy represents an even greater nutritional stress situation in that the adolescent still has her own growth requirements and is more likely to be subject to bizarre eating habits. Nutrition has been a sadly neglected field and we need to provide an education in this area to both the potential parents and to the health service personnel taking care of them.

This synopsis of a few of the many pre-conception influences on the occurrence of developmental disabilities is meant to provide the task forces with a starting point for their discussions. I am sure many other such influences will be brought forth in these discussions. I look forward to the exciting task of formulating recommendations that can be used at a legislative and administrative level to help lower the incidence of developmental disabilities.

THE PREVENTION OF MENTAL RETARDATION AND GENETIC DISEASE EARLY PREGNANCY

by
Aubrey Milunsky, MB.B.Ch., M.R.C.P., D.C.H.

Recognition of Causes

The essence of prevention is the recognition of cause. For mental retardation, this implies the need to recognize three major etiological categories:

1. Genetic
2. Acquired
3. Unknown

The relative impact that these three categories have on the causation of developmental disabilities will be discussed. Clearly the "genetic burden" is significant from many points of view, and especially reflected in the fact that approximately 20-25% of all major teaching hospital pediatric admissions are for birth defects in the widest sense.

At the very base of any successful program in the prevention of mental retardation, must be the well-supported effort aimed at the continuing search for the causes of mental retardation. On such a base, a program of prevention can be built and will be discussed in the following eight categories.

Genetic Counseling

Medical practice in the past – and therefore genetic counseling too – has rested on the philosophy of awaiting the tragic index case. Viewed against the background of the call for quality offspring, it would seem mandatory for society to provide all young people with the option of receiving genetic counseling prior to marriage or conception of any offspring. Interim measures should at least secure such counseling for the siblings and close relatives of many different genetic diseases.

Carrier Detection

There are two levels of approach in this category. Firstly, there is a remarkable lack of effort in carrier detection within families where such possibilities do exist, e.g., hemophilia, muscular dystrophy, translocation mongolism, sickle cell anemia, etc. Recent advances in medical technology have facilitated the ability to detect carriers for certain hereditary diseases in the population at large. Large screening programs with this aim in mind have been launched for Tay-Sachs disease and sickle cell anemia. The technologic essence here is the availability of automated, inexpensive, reliable, accurate and relatively simple testing procedures. Major

difficulties in these endeavors have been ethical rather than technological. The number of disorders in which carrier detection is possible on a population basis is steadily increasing.

Prenatal Diagnosis

The prenatal diagnosis of hereditary disorders will in the immediate future allow for the prevention of up to 15% of all genetic defects. The present problem is that even though the technology is available, the vast majority of people who could benefit from prenatal genetic studies, are not being tested. There are for example, over 20,000 children born with chromosomal abnormalities each year in the USA alone. In 1973, only about 50 such abnormalities will have been diagnosed in utero! There must be a number of important reasons that prevent the public at large from benefiting from available knowledge and technology. Religious affiliations, problems concerning abortion and professional and public ignorance feature prominently among these causes for delay. Important technologic advances making prenatal diagnostic studies even more valuable continue to occur. The use of ultrasound and more recently, the introduction of alpha-fetoprotein as a diagnostic adjunct in the management of pregnancies at risk for offspring with neural tube defects well illustrate the need for applying this information to the population at large. The advent of prenatal genetic diagnosis represents the most significant advance yet in the prevention, through early detection, of serious/fatal genetic disease characterized by mental retardation.

Treatment

Phenylketonuria stands out as the classical example of successful dietary prevention of mental retardation in the hereditary biochemical disorders of metabolism. Less impressive have been the results with dietary management of some of the other inborn errors of metabolism characterized by mental retardation. Success however, in dietary management is totally dependent upon newborn screening and the rapid initiation of dietary therapy. Such population screening must be efficient, accurate and all encompassing. Most states do not provide as complete a coverage as Massachusetts in covering a number of the inborn errors of metabolism.

Immunization

Approximately 10% of women in the childbearing age in the USA are susceptible to rubella. The havoc caused by epidemics of rubella so far as the offspring of affected pregnant women are concerned, was well recognized by the over 20,000 affected infants in the mid-60's epidemic. In most states there is still no program in which there is routine testing of the mother to determine her susceptibility, or alternatively the provision of vaccines.

Regionalization

The more sophisticated the service offered, and the greater the expertise needed to dispense that service, the more important is it for regionalization to occur. In Massachusetts for example, my laboratory has been designated the central state facility for prenatal diagnosis of genetic disorders. Complete genetic counseling can also not be offered in every physician's office. Indeed a team approach is not only

desirable, but necessary in providing proper genetic counseling. The need to have traveling genetic clinics has already been met in Boston, Denver and elsewhere.

Other major topics considered in this talk included a consideration of the need for *education* (public and professional), the ethical and other problems in the promulgation of *legislation*, and the various *socioeconomic* aspects and implications of preventive programs.

PREVENTION OF DEVELOPMENTAL DISABILITIES IN LATER PREGNANCY AND DELIVERY

by

A. H. Parmelee, M.D. and Claire B. Kopp, Ph.D.

Part 1 – A. H. Parmelee

As a pediatrician I am not prepared to discuss preventive measures obstetricians might best employ during late pregnancy and delivery. I am concerned with the early identification of those infants who suffer later development disabilities as a consequence of problems in late pregnancy and during delivery. Although we speak freely of high risk pregnancies and infants at risk as a result of perinatal complications, in fact, we don't know the degree of risk for later developmental disabilities for any particular late pregnancy or delivery problem. Our current concept of "risk" is based almost entirely on risk for death or serious illness in the neonatal period.

With the fragmented information we have there is some justification for stating that fetuses and infants at risk of death, if they survive, may also be at greater risk for later developmental disability than non-risk infants. This idea is based on the concept of a "continuum of casualty" and sublethal components. The lethal components include abortions, still births and neonatal deaths and the sublethal components, neonatal illness, and later developmental disabilities. The difficulty with this concept is that it focuses our attention almost exclusively on those infants who suffer events that cause neonatal death. However, the great majority of the surviving infants do not have later developmental disability even though the infant appeared to have neurological impairment in the neonatal period. Much of the trauma of acute perinatal events causes only transient brain insult rather than lasting brain injury. Furthermore, the concept of a continuum of casualty also takes our attention away from infants who may have suffered chronic intrauterine deficiencies of nutrients or oxygen but adapt well enough to survive and have no neonatal difficulties, but shows a significant incidence of later developmental disability.

Another problem with the continuum concept was brought forcefully to our attention by the failure of "infant risk registers" in England in the 1960's. So many perinatal problems were considered to place an infant at risk for later developmental defect that often as many as 60% to 70% of all infants born in a district were on the risk register. Thus it was not very discriminating and, in addition, by school age most of these children were doing well. Furthermore, a significant number of school children with developmental defects were identified who had not been on the risk register.

More recently the data from the National Institute of Health collaborative project, with prospective follow-up of 40,000 pregnancies, found no or only minimal differences on childhood intelligence tests between those infants who suffered single abnormal perinatal events and those who suffered none. The socio-economic status of the children's parents was a far more significant factor in determining intelligence scores than any single perinatal event.

As physicians, our primary responsibility is to prevent neonatal death and illness so we will continue to focus major attention on this form of risk to the extent the concept of continuum of casualty is valid for later developmental disability in attending to the first form of risk we will also diminish the latter. However, I think it is particularly important for this conference to point out that this is a limited approach and by no means sufficient to prevent all forms of developmental disability related to later pregnancy and delivery problems.

We need to devise new ways of identifying in early infancy deviant development that persists and is highly related to later developmental disabilities. Currently many investigators are looking at clusters of pregnancy and neonatal events that may interact cumulatively, and, combined with neonatal and early infancy behavioral assessment be significant predictors of later developmental disability. Certainly the development of centers for the care of high risk pregnancies and high risk newborns in the traditional sense will aid in the development of new techniques.

Part 2 – Claire B. Kopp

Developmental disability, that has its origins in the later pregnancy and delivery period, can be investigated using the prematurely born infant as a model. Prematures, as a group, have a higher incidence of developmental disabilities than do full term infants. However, analyses of research data on prematurity and its outcome suggest that a simple cause and effect relationship does not exist between premature birth and poor emotional, linguistic, and intellectual outcome during childhood. Many premature infants develop into children with no or minimal problems.

However, there are two classes of variables that may place infants into a category of developmental risk. One is that prematurity may be associated with many other problems of later pregnancy, delivery, and the neonatal period. These are subsumed under the concept of multiple risk measures. The second class of variables relates to the infant in his milieu, and ensuring family interactions. These latter variables are the focus of this part of the presentation and include an examination of: (1) infant attributes that may influence the interactive process; (2) the caretakers' contribution to the interactive process; and (3) the social-cultural milieu of the family. It is the particular combination of these variables that may distort, impair, or enhance the ongoing development of the infant.

The infant's influence on his caretaker may derive from the following:

1. Infant labeled as "premature." The label itself implies "risk" and affects parents' attitudes and actions toward their child. Parent-infant attachment may be impaired due to parental anxiety and guilt about the infant.

2. Postnatal illness. Complications may arise in the early infancy period, perhaps prolonging the parent-infant separation, and exacerbating parental fears about the infant's health and potential outcome.

3. Constitutional characteristics of the infant. Premature infants may have eating, sleeping, and crying patterns that deviate from parental expectations leading to recurrent interaction crises.

4. Elaboration of behavior. The laws of development determine that an infant's emotional, motoric, social, and cognitive abilities become more skilled and complex over time. Such changes demand concomitant changes in parents' actions toward their child.

5. Sum totality of infant behaviors. Almost everything that an infant is, or does, affects his caretakers' responses to him.

The parent's behavior toward the infant may derive from the following:

1. Emotional strengths of parents. The ability of parents to respond appropriately to crises over premature birth, or subsequent illnesses of the infant, will have a profound effect on early interactions.

2. Education and intelligence of the parents. Parental understanding, resources, and ingenuity are vital factors that contribute to understanding of an infant's development, his present and potential needs, and how he may differ from other children.

3. General nature of parenting. The responsiveness of a parent to the infant's vocal or gestural communications, actions, explorations, etc., may influence the infant's subsequent active interest in learning about objects and people in his surroundings.

4. Parents' other responsibilities. These may involve siblings, job, extended family members, etc., and demand and tax parental resources at a time when their infant is in need of considerable attention.

The social milieu may influence the family constellation due to the following:

1. Perception of "society." When parents perceive that their immediate environment is not hostile, and can provide an opportunity for stability in terms of job, health care, adequate nutrition, education, etc., then attention can be paid to non-physical needs of family members.

2. Perception of "control." When parents feel that they exercise control over their own lives, and their future, they also feel they can influence and promote healthy development in their children.

In summary, there are many complex processes that operate to determine developmental disability. We have mentioned a few that we consider very important. Fortunately, the search to understand and define these processes continues, and is being aided by increasing use of sophisticated statistical techniques.

THE INFANT AND YOUNG CHILD

by

John Meier, Ph.D.

The validation of screening instruments and systems has been undertaken with older preschool and elementary school children (Bakalis, 1972; Denhoff, 1969; Hoffman, 1972; Meier, 1971; Sandler, 1972; and Wyatt, 1971) and might prove instructive for designing validation studies with infants and younger children. The following page (Table 1) presents an Annotated Index of various representative developmental screening tests and procedures which were selected as being designed and more or less appropriate for infants and toddlers. It can be readily determined that there are very few, if any, adequate single instruments for primary or subsequent screening and assessment of young children at developmental risk. However, a careful combination of such instruments at appropriate stages and chronological ages promises to comprise a satisfactory comprehensive system.

Beyond the Paralysis of Analysis

When a satisfactory comprehensive developmental screening system has been field-tested and thoroughly debugged, it is only useful if it plugs into practical intervention programs. Several successful intervention programs have been reported in the literature. Table 2 presents a matrix of screening, evaluation, and intervention considerations in a composite and self-explanatory format. It is obviously beyond the purview of this summary to elaborate upon the various procedures, instruments, and model programs indicated at various strategic points in the matrix. Needless to say, it is most desirable for any potential subject in this system to begin and remain normal, thus progressing down the left column. However, for those who yield positive screening results and are subsequently found to have *bona fide* developmental delays or disabilities, the sooner it is the better it is that they are identified and placed in properly matched remediation/prevention programs (examples of which are mentioned in the right column). Since individual subjects and individual professionals and paraprofessionals bring various requirements to each case, several options are presented in the evaluation and intervention columns.

TABLE 1

APPENDIX A: ANNOTATED INDEX FOR SELECTED DEVELOPMENTAL SCREENING TESTS AND PROCEDURES

Developmental Domain	Page[1]	Test or Procedure	Developer(s) Author(s)	Age Range[2]	Reliability	Validity	Time[5]	Cost per Child[6]	Administration[7]	Recommended Stage[8]
PHYSICAL	30	Automated Multiphasic Health Testing Services	Collen & Cooper	Over 4 yr.	A[3]	A	70	30[9]	Mix	Ter.
	34	Biochemistry & Cytogenetics	Guthrie	5-3 mo.	A	A	U[4]	<1	LT&EE	Sec.
	38	Amniocentesis	O'Brien	C-B	A	A	60	20	P	Sec.
	40	Metabolic	Howell, Holtzman & Thomas	B-3 mo.	A	A	<30	2	LT&EE	Sec.
	41	Ultra-Micro Automated System	Ambrose	B-3 mo.	A	A	60	1	Mix	Sec.
	42	Nutritional Status	Fomen	B-30 mo.	A	U	20	1	PP	Sec.
	44	Gestational Age	Lubchenco	B-1 mo.	A	A	5	2	PP	Sec.
	49	Statistical Mortality Morbidity	MCH	B-12 mo.	A	A	Neg[9]	Neg	P	Pre-Pri
	51	Statistical Epidemiology	Tarjan, et al.	Pre-B	A	A	Neg	Neg	P	Pre-Pri
	55	Data System	Scurletis, et al.	Pre-B	A	A	Neg	Neg	PP	Pri
	57	Prevention	de la Cruz & LaVeck	Pre-C	U[4]	U	U	U	P	Pri & Pre-Pri
	58	Apgar Rating	Apgar	B	A	A	6	1	P	Pri
	59	Vision	Press & Austin	Over 30 mo.	U	U	Neg	1	PP	Pri
	61	Eye Screening	Barker & Hayes	B-5 yr.	U	U	Neg	<1	PP	Pri
	62	Electro-Oculograph	Petre-Quadens	1-6 yr.	A	U	120	10	LT&EE	Ter.
	64	Hearing High-Risk Register	Hardy	C-3 yr.	A	U	Neg	Neg	PP	Pri
	67	Hearing Screening	Young; Downs & Silver	9-1[illegible] mo.	A	A	5	2	PP	Pri
	71	Potential Battered Children	Kempe & Helfer; Walworth & Metz; Gil	C-2 yr.	U	U	U	U	P	Sec.
	73	Vocalization Analysis	Fillippi & Rousey	B-12 mo.	U	U	40	20	PP	Sec.
	75	Behavioral & Neurological Assessment Scale (I)	Brazelton	B-3 yr.	A	U	40	30	P	Ter.
	75	Neuro-Developmental Observation	Ozer & Richardson	Over 5 yr.	U	U	20	15	PP	Sec.
INTELLECTUAL/ COGNITIVE	80	Attention to Discrepancy	Kagan	B-12 mo.	A	U	30	20	LT,EE	Ter.
	83	Ordinal Scales of Cognitive Dev.	Uzgiris & Hunt	B-3 yr.	U	U	60	30	PP	Sec.
	86	Infant Intelligence Scale (CIIS)	Cattell	B-30 mo.	A	A	25	15	P	Sec.
	86	Bayley Scale of Infant Dev.	Bayley	B-30 mo.	A	A	45	25	P	Sec.
	88	Kuhlmann-Binet Infant Scale	Kuhlmann	B-30 mo.	A	A	30	15	P	Sec.
	88	Griffiths Mental Dev. Scale	Griffiths	B-4 yr.	A	A	30	15	P	Sec.
	89	Gesell Developmental Scale (Revised Scale)	Gesell, et al.	B-5 yr.	A	A	40	30	P	Sec.
	92	Ivanov-Smolensky	Luria	B-24 mo.	A	U	20	15	LT	Ter.
	93	Habituation	Lewis, et al.	B-18 mo.	A	A	30	15	PP	Sec.
	93	Psychophysiological	Crowell	B-3 mo.	A	A	80	50	Mix	Ter.
LAN-GUAGE	98	Playtest	Friedlander	3-12 mo.	A	A	50	25	LT,EE	Ter.
	99	Infant Cry Analysis	Ostwald, et al.	B-3 mo.	A	U	30	15	LT,EE	Ter.
	104	Expressive Language	Reyes, et al.	2-4 yr.	A	A	40	20	PP	Sec.
	108	Receptive Language	Marmor	1-3 yr.	A	U	30	15	PP	Sec.
	108	Early Language Assessment Scale	Honig & Caldwell	3-48 mo.	A	U	30	15	PP	Sec.
SOCIAL/ EMOTIONAL	114	Behavioral & Neurological Assessment Scale (II)	Brazelton, et al.	B-3 yr.	A	U	30	15	PP	Sec.
	114	Behavior Problem Checklist	Quay & Peterson	B-4 yr.	U	U	30	20	P	Sec.
	116	Rimland Diagnostic Check List	Albert & Davis	B-4 yr.	U	U	30	20	P	Sec.
	116	Behavior Checklist	Ogilvie & Shapiro	3-6 yr.	A	U	45	30	P	Sec.
	117	Quantitative Analysis of Tasks	White & Kaban	1-6 yr.	A	A	60	30	PP	Sec.
	118	Behavior Management Observation Scales	Terdal, et al.	B-4 yr.	U	U	60	20	PP	Sec.
	118	Vineland Soc. Maturity Scale	Doll	B-18 yr.	A	A	25	10	PP	Pri/Sec.
	118	Preschool Attainment Record	Doll	B-7 yr.	A	U	30	15	PP	Pri/Sec.
	119	Behavioral Categorical System	DeMyer & Churchill	2-5 yr.	A	U	30	20	P	Sec.
	125	Psychological Assessment: Functional Analysis	Bijou & Peterson	B-Adult	A	A	U	U	P or PP	Ter.
COMPREHENSIVE SYSTEMS	128	First Identification of Neonatal Disabilities (FIND)	Wulkan	B-12 mo.	U	U	U	U	U	All
	128	System of Comprehensive Health Care Screening & Service	Scurletis & Headrick	C-4 yr.	A	U	U	U	Mix	All
	132	Preschool Multiphasic Program	Belleville & Green	B-4 yr.	A	A	U	U	Mix	All
	136	Pluralistic Assessment Project	Mercer	5-11 yr.	U	U	U	U	U	Sec.
	140	Pediatric Multiphasic Program	Allen & Shinefield	Over 4 yr.	A	A	120	30	Mix	All
	143	Rapid Developmental Screening Checklist	Giannini, et al.	B-5 yr.	A	A	5	1	PP,P	Pri
	143	Guide to Normal Milestones of Development	Haynes	B-3 yr.	A	A	15	5	PP,P	Pri
	150	Developmental Screen, Inventory	Knobloch, et al.	5-18 mo.	A	A	20	10	PP,P	Pri
	153	CCD Develop. Progress Scale	Boyd	B-8 yr.	A	A	30	15	PP	Pri
	156	Denver Develop. Screening Test	Frankenburg & Dodds	B-6 yr.	A	A	30	15	PP	Pri
	16	At Risk Register	Alberman & Goldstein, Sheridan; Oppe; Walker	Pre-C	A	A	Neg	Neg	PP,LT	Pre-Pri.
	19	Risk Factors (Kauai Study)	Werner, Bierman & French	Pre-C to 12 yr.	A	A	Neg	Neg	PP	Pre-Pri.

NOTES:
1. Number of first page discussing topic in *Screening and Assessment of Young Children at Developmental Risk* (by Meier, J. H., Wash., D.C., Gov't. Printing Office, 1973).
2. C=Conception; B=Birth.
3. A=Adequate, i.e., >.75, when reported or estimated (only concurrent and face validity — not predictive).
4. U=Unknown — in any category indicates that data are either unavailable, too variable, or sparse.
5. Minutes required for administration and interpretation — estimated average with normally developing child.
6. Estimated total in dollars including time and materials under optimum conditions.
7. P=Professional trained to administer test(s); PP=ParaProfessional, properly trained; LT=Laboratory Technician; EE=Elaborate Equipment (in laboratory and usually not portable); Mix=Combination of preceding. A trained professional is required to interpret test results.
8. Recommended Stage in Screening System — Pri=Primary; Sec.=Secondary; Ter.=Tertiary; Pre-Before.
9. Neg.=Negligible amount of time or cost per child.

TABLE 2

SCREENING, EVALUATION, AND INTERVENTION FOR YOUNG CHILDREN AT DEVELOPMENTAL RISK*

Age	Satisfactory Progress If not →	Screening and Risk Assessment If screening results or risk factors are positive →	Evaluation, Close Observation and Diagnosis to →	Intervention and Follow-Along →
PRE-CONCEPTUAL	Intent to Conceive Adaptive & Physiological Readiness (Normal Maternal & Family History)	**Presence of One or More Maternal Risk Factors:** Physical/Medical 1. Malnutrition 2. Age < 16 or > 35 3. Poor Reproductive History 4. Suspect Metabolic and/or Genetic Disease Social/Behavioral 1. Low SES 2. Sixth Grade Education 3. Functionally Illiterate 4. Low Adaptive Behavior Rating	Nutritional/Metabolic Tests Derive Genetic Pedigree Literacy/Educ. Tests Adult Adaptive Behavior Rating (Nihira)	Genetic Counseling (Sterilization) Diet Therapy Contraceptive Counseling (Planned Parenthood) Maternal Training (Jr. & Sr. High School)
PREGNANCY (first 3 mo.)	Request for Service (Suspected Pregnancy Confirmed) Regular OB/GYN Checks Normal Progress	**Complications During Pregnancy:** 1. Infections 2. Rubella 3. Toxemia 4. Drug Overuse 5. Radiation 6. Blood Incompatibility 7. Malnutrition 8. Maternal Psychosis 9. Unwanted Pregnancy	Appropriate Medical Tests to Evaluate Maternal & Embryo Condition Amniocentesis Social/Behavioral Tests of Maternal Ability and Attitudes	Counseling Therapeutic Abortion Psychotherapy
(last 3 mo)	Regular OB/GYN Checks Normal Progress	Above First Request for OB/GYN Services	Evaluation of Maternal and Fetal Condition	Counseling Positive Attitude (Natural Childbirth)
NEWBORN (first month)	Hospital Admission Normal History of Pregnancy and Routine OB/GYN Checks Uneventful Delivery	**Complications During Delivery:** 1. Hemorrhage 2. Dystocia 3. Excessive Anesthesia 4. Trauma 5. Placental Damage 6. Cesarean 7. Premature (SGA) 8. Postmature 9. Hospital Admission with no prior OB/GYN checks	Appropriate Medical Tests to Evaluate Maternal & Infant Condition	Necessary Procedures to Insure Maternal & Infant Viability
INFANCY	Normal Neonatal Growth & Development	**Pediatric Physical and Developmental Exam:** 1. Apgar (5 min.) 2. Metabolic/Genetic Screens (e.g., PKU) 3. Trauma 4. Infection 5. Malnutrition 6. Head Circumference 7. Guide to Normal Milestones of Development (@ 1 mo.)	Behavioral & Neurological Assessment Scale (Brazelton & Harowitz, @ 1 mo.) Environmental Quality Maternal Attitude & Aptitude (Below for Specifics)	Sensory Stimulation Behavior Modification Environmental Enrichment Maternal Training (Below for Specifics)

*Developed by John H. Meier for Governor's Conference on Prevention of Developmental Disabilities, held at Newporter Inn and University of California (Irvine), December 1973. The author gratefully acknowledges the suggestions from Tadashi Mayeda regarding the format of this matrix.

	Satisfactory Progress If not →	Screening and Risk Assessment If screening results or risk factors are positive →	Evaluation, Close Observation and Diagnosis to →	Intervention and Follow-Along →
INFANCY	Monthly Well-Baby Physical & Developmental Checks (1st year) Normal Progress Bi-Monthly Physical & Developmental Checks (2nd year)	Physical: 1. Trauma 2. Infection 3. Diseases 4. Malnutrition 5. Vision 6. Hearing 7. Maternal Postnatal Depression/ Rejection, Neglect and/or Abuse 8. Prolonged Separation of Infant from Mother Developmental: 1. Rapid Developmental Screening Checklist (@ 6 mo. and 1 yr.) 2. Developmental Screening Inventory (@ 18 mo.) 3. Developmental Progress Scale (@ 12, 18, 24 mo.) 4. Denver Developmental Screening Test (@ 12, 18, 24 mo.) 5. Behavior Problem Checklist (@ 24 mo.)	DQ: Albert Einstein Scales of Sensori-Motor Development; Fantz-Nevis Visual Preference Test; White-Held Visually-Directed Prehension Test; Gesell Developmental Scale; Bayley Scale of Infant Development Cognitive Q: Ordinal Scales of Cognitive Development; Griffiths Mental Development Scale; Kahn Intelligence Tests; Infant Rating Scales (Hoopes); Kuhlman-Binet Infant Scale; Infant Intelligence Scale Environ./Parent Q: Caldwell (A Procedure for Patterning Responses of Adults and Children – APPROACH); Parental Attitude Research Instruction; Parents' Attitude Scale; Hechsler Adult Intelligence Scale (WAIS) Language Q: Irwin Speech Sound Development Test; Prelinguistic Infant Vocalization Analysis (Ringwell, et al.); Shield Speech and Language Development Scale; Early Language Assessment Scale (Honig); Receptive-Expressive Emergent Language (REEL, Bzoch) Ach. Q: Preschool Attainment Record (Caldwell) P/N Q: Psychophysiological/Neurological Maturity (Brazelton, Crowell) Soc./Behav. Q: Vineland Social Maturity Scale (Doll); Emotional Maturity Adaptive Behavior Scales (Nihira); Pluralistic Assessment (Mercer)	Bobath & Ayres (Physical Therapy) Gordon (Home Learning Center – Florida) Gray, et al. (DARCEE) Heber & Garber (Milwaukee Project) Keister (North Carolina Infant Day Care) Lally & Honig (Syracuse Infant Project) Levenstein (Mother-Child Home Program) Parent-Child Center Programs (Costello, Holmes) Meier, et al. (Education System for High-Risk Infants) Robinson (Frank Porter Graham Infant Project) Weikart & Lambie (Ypsilanti-Carnegie Infant Education Project) White & Kaban (Brookline)
TODDLER – EARLY CHILDHOOD	Periodic Physical & Developmental Checks Approximately every 6 mos.) Normal Progress	Pediatric Physical Exams (See above considerations) Developmental Screens (Nos. 4, 5, & 6 above) Peabody Picture Vocabulary Test Goodenough-Harris Draw-A-Person	Preschool Inventory (Caldwell) Leiter International Performance Scale Slosson Intelligence Test Raven's Coloured Progressive Matrices Stanford-Binet Intelligence Scale Developmental Articulation Test (Hejna) Illinois Test of Psycholinguistic Abilities (Kirk & McCarthy) Verbal Language Development Scale (Mecham) Developmental Test of Visual-Motor Integration (Beery) Developmental Test of Visual Perception (Frostig) Detroit Tests of Learning Aptitude Minnesota Preschool Scale IPAT Test of G-Culture Fair (Cattell) Arthur Point Scale of Performance Tests California Tests of Mental Maturity and Personality Metropolitan Readiness Test Oseretsky Tests of Motor Proficiency Weoman Auditory Discrimination Test	Model Preschool Programs (by last names of developers – for description, see SOURCES below). Anderson & Bereiter Blank Hooper Kamii Karnes, Zehrbach, & Teska Meier Miller & Camp Montessori Nedler Nimnicht Palmer Robison Shaeffer & Aaronson Weikart Whitney & Parker

SOURCES: Battle, C. U. & Ackerman, N. C. *Early Identification and Intervention Programs for Infants with Developmental Delay and Their Families – A Summary and Directory*. Chicago: Nat'l. Easter Seal Society for Crippled Children & Adults, 1973. Guthrie, P. D. with Horne, E. V. *Measures of Infant Development – An Annotated Bibliography*. Washington, D.C.: Head Start Test Collection, Educational Testing Service, December 1971. Hoepfner, R., Stern, C. & Nummedal, S. G. (Eds.), *CSE-ECRC Preschool/Kindergarten Test Evaluations*. Los Angeles, Calif.: UCLA Graduate School of Education, 1971. Meier, J. H. *System For Open Learning, Facilitator's Handbook I: SOL Foundations and Rationale*. Denver, Colo.: Publisher's Press Inc./Monitor Publications, 1973. Meier, J. H. *Screening and Assessment of Young Children at Developmental Risk*. Washington, D.C.: U.S. Gov't. Printing Office, 1973. Parker, R. K. (Ed.), *The Preschool in Action – Exploring Early Childhood Programs*. Boston, Mass.: Allyn and Bacon, Inc., 1972. Williams, T. M. *Infant Care – Abstracts of the Literature*. Washington, D.C.: Consortium in Early Childbearing and Childrearing, August 1972.

THE RECOMMENDATIONS

The following eight recommendations were the most frequently mentioned during the two days of intense deliberations by the more than 200 persons who attended the conference.

Actions on education and public awareness received the most support by conferees. Recommendations in these areas were aimed at all state agencies, professional societies, educational institutions, local health and educational agencies and all other organizations allied with health and education which could reach and influence the general public to accept and use the knowledge of prevention that is now available.

The following recommendations represent a composite of 91 recommendations proposed during the conference.

A complete text of the entire 91 recommendations is on file in the Office of Developmental Disabilities, Health and Welfare Agency, Sacramento, California.

RECOMMENDATION NO. 1

Provide education and information pertaining to the prevention of developmental disabilities to all Californians and, in particular, to adolescents, prospective parents, and all practicing professionals.

Child development courses in elementary and secondary schools, both public and private, must be taught to all children and must include the teaching of practical, appropriate, current knowledge of human development, nutrition, human genetics, effective parenting, and the effects of certain aspects of environment on normal development.

It is strongly recommended that continuing education of practicing professionals include current research findings of primary and secondary prevention and the application of those resources that are available to counteract unfavorable influences on normal growth and development.

It is necessary to bring to the attention of the general public the fact that disregarding the care of any one of the 360,000 infants born each year in California, will result in lifelong emotional and financial consequences.

RECOMMENDATION NO. 2

Coordinate and, where necessary, expand services to prospective parents, expectant mothers, newborns and their parents, so as to provide comprehensive and continuous coverage from pre-conception through delivery and early infancy.

Agencies which provide family services, maternal and infant care, well-baby clinics, genetics services, intensive newborn care, perinatal care, immunization services, crippled children's services, and other directly and indirectly related services are at present located throughout California. The care provided to prospective parents, expectant mothers, newborns and their parents is, however, inconsistent and uneven. Such agencies should be so well-coordinated that no person would lack comprehensive care.

Working relationships between comprehensive service centers and special family and health care centers should be coordinated so that specialized care, when required, is both available and accessible.

Genetic counseling services and intensive newborn care centers must be additionally developed, expanded, and coordinated to make them available to all persons in need of them.

RECOMMENDATION NO. 3

Provide expectant mothers and newborns with full range of supportive services. Regulations governing pre-paid health plans and third party payment should assure adequate benefits.

RECOMMENDATION NO. 4

Offer expanded family planning and prenatal services to women of child-bearing age, expectant mothers and prospective parents, in such a way that they are made dramatically aware of the important responsibility of those who will provide the future of the nation.

Free pregnancy tests should be considered as an inducement for early prenatal services.

Appropriate immunizations (Rubeola, Rhogam, etc.) should be available at no or minimum cost.

The media should be used extensively to inform and educate prospective parents on effective parenting. This must be followed up with selective food allotments, transportation assistance and home help.

Services should include regularly scheduled comprehensive screening to detect early signs of need for supportive services, by stationary and mobile units.

RECOMMENDATION NO. 5

Review and assess the preventive services provided through regional centers and critically assess their capacity to undertake a full range of preventive programs.

Except for genetics and other services directly linked to developmental disabilities, it is suspected that the ability of regional centers to undertake comprehensive preventive services is limited. Their role in prevention should be expanded so that their authority to assist in educational and public information ventures is increased and their authority to purchase related services is broadened.

RECOMMENDATION NO. 6

Survey existing manpower needs in already existing family, prenatal, and newborn services to determine the numbers, classifications and distribution of personnel required to provide comprehensive care from pre-conception through delivery and early childhood.

The development of new, allied professions should be considered and efforts made to expand the availability of services through greater use of family nurse practitioners, mid-wives and others.

The content of courses and the scheduling of classes should be more responsive to the current needs of practicing professionals.

The content of community college courses should include an emphasis on the training of personnel for comprehensive human care.

RECOMMENDATION NO. 7

All state supported or subsidized preventive services should be required to maintain individualized client records reflecting the effectiveness of services. This recommendation is not to be confused with the development of a central risk registry, which was not endorsed by the conferees. It is, rather, a means to assure accountability.

RECOMMENDATION NO. 8

Related professional accreditation boards and societies, educational institutions, regulating agencies, and selected service organizations must jointly develop standards which will result in high quality care and training in family, prenatal, delivery, newborn, and early childhood services.

The Department of Health and Department of Education have the jurisdictional responsibilities to initiate such coordinating actions.

The Participants

THE PRE-CONCEPTION PERIOD
GROUP 1
B. Otis Cobb, M.D., Moderator
Yolo County Health Department
Marylou Buyse, M.D., Recorder
USC School of Medicine

Dennis Amundson
Assembly Minority Ways
and Means Committee
Sacramento

Miss Marilyn Anderson
March of Dines
Chico

Dr. Margaret Basham, President
California School Health Association
Hillsborough

Mrs. Elizabeth Bible
Orland

Robert E. Carrel, M.D.
Medical Director
Tri-Counties Regional Center
Santa Barbara

James Chin, M.D., Chief
Infectious Disease Section
Department of Health
Berkeley

Kenneth W. Dumars, M.D.
Associate Professor
University of California
Irvine

Joan Ell, Chief Counselor
Harbor Regional Center

Marjorie P. Honzik, Ph.D.
University of California
Berkeley

Mr. Ralph D. Levy, Director
Alta California Regional Center
Sacramento

Sister Ann Marita
Administrator
Kennedy Child Study Center
Santa Monica

Dr. Albert Marshall, Jr.
Coordinator, Special Education
California State University
Chico

Jacqueline Montgomery, Ph.D.
Camarillo State Hospital

Gregario Pineda, M.D.
Kern Regional Center
Bakersfield

Francis D. Riggs, M.D.
Area Board VI Chairman

Rhona Rudolph, M.D.
Medical Director
San Francisco

Helen Schulz, M.D.
Director, Maternal and Child Health
Santa Barbara

Mr. Donald Stockman
Acting Chief
Regional Center Section
Department of Health
Sacramento

Jackie Tatum
Supervising Counselor
Central Valley Regional Center
Fresno

Felice Weber, M.D.
Tri-Counties Regional Center
Santa Barbara

David Whyte, M.D.
Medical Director
Far Northern Regional Center
Redding

Miriam Wilson, M.D.
University of Southern California
School of Medicine
Los Angeles

THE PRE-CONCEPTION PERIOD
GROUP 2

Betty Woodward, M.S.W., Moderator
UC—Irvine
Jerre Lender, Ph.D., Recorder
UC—Irvine

Walt Ballard, M.D.
Ventura County General Hospital
Ventura

Wilbert C. Bradshaw, Member
State Developmental Disabilities
Planning & Advisory Council
Fresno

Mrs. Margarete Connolly
Executive Director
San Francisco Aid Retarded
Children, Inc.
San Francisco

Ms. Regina Eddy, President
California School Nursing Organization
Long Beach

Clare Engle, Representative
League of Women Voters
Santa Ana

Irene Forsman, R.N.
University of Southern California
Medical Center
Los Angeles

Anne Gabel
Fresno

Fred A. Gideion
North Bay Regional Center
Napa

Glynn Gregory
Project Psychologist
Redding

Mrs. Raymond Hudson
Redwood Valley

Mrs. Bessie Kay, Chairman
Area Board II
Redding

Robert L. Lundak, Ph.D.
Department of Pediatrics
University of California, Irvine

Mrs. Joyce Lundak
University of California, Irvine

Andrew Pollard
MR Program
Neuropsychiatric Institute — UCLA

Ms. LaVesta Reeves
Rialto

Martin J. Rosenfeld, M.D.
Medical Director
Children's Hospital of
Orange County

Arthur C. Sanborn
Associate Director
Service to Rural Isolated Children
Redding

David Satcher, M.D.
Drew School
Martin Luther King Hospital
Los Angeles

Ruth Thomas, Chairman
Central Valley Section
Department of Education
Visalia

Jane Welker
Early Childhood Education Center
University of California, Davis

William Wiedner
Department of Health
Sacramento

Verlin Woolley
Program Director
San Bernardino

EARLY PREGNANCY
GROUP 1
Mary Fenley, R.N., F.N.P., Moderator
UC–Davis
Barbara Crandall, M.D., Recorder
UCLA–Neuropsychiatric Institute

Bruce Becker
Placer County
Department of Education
Auburn

Vern Beckett
First Vice President
California Association for the
Retarded
Sacramento

Mr. Don Brecker
California State University
Chico

Helen Brown
Health Coordinator
Orange County Board of Education
Santa Ana

Elisabeth Charron
Family and Children Services
Advisory Committee
Garden Grove

Lorraine de Graff, R.N.
Children's Hospital Medical Center
Los Angeles

Barbara Dixson, R.N., M.N.
Children's Hospital & Health Center
San Diego

Mr. Raymond Hudson, Chairman
Area Board I
Redwood Valley

Mrs. Ann Ivey, R.N., Chairman
Area Board XII
San Bernardino

Richard Koch, M.D.
Medical Director
Regional Center for the MR
Children's Hospital – Los Angeles

Dr. Jane Lewis
Department of Home Economics
California State University
Los Angeles

Michael E. Ogle, Ph.D.
Chief Psychologist
Tri-Counties Regional Center
Santa Barbara

Jean Paulson
Harbor Regional Center
Torrance

Ms. Lou Vera Ross
Rialto

Richard Saladana
Easter Seal Society of
Placer County
Auburn

Betty F. Shelton, M.D.
Medical Director
Porterville State Hospital

James T. Shelton
Porterville State Hospital

Mrs. Gwendolyn Stephens, Member
State Developmental Disabilities
Planning & Advisory Council
San Diego

Mrs. Pat Sterling
Davis

Mrs. Dorothy Sutherland
Executive Director
National Foundation
March of Dimes – Santa Ana

Dale Thorsted
Superintendent of Schools Office
Redding

EARLY PREGNANCY
GROUP 2
Allan Ebbin, M.D., Moderator
USC School of Medicine
George Limbeck, M.D., Recorder
Children's Hospital of Orange County

Sharon Bintliff, M.D.
Children's Hospital
Hawaii

Ms. Carol Bitcon
Program Director
Fairview State Hospital
Costa Mesa

Dale Curtis
State Department of Rehabilitation
Sacramento

Gayle Fialko
University of California
Irvine

Ms. Beth Hadady
Supervising School Nurse
Pomona School District
Glendora

Helen Hamaguchi
Children's Hospital – Los Angeles

Wylda Hammond, M.D.
University Affiliated Program
Children's Hospital Medical Center
Los Angeles

Jack Hoxsie, Staff Member
Area Board XI
Santa Ana

Oliver Jones, M.D.
Department of Medicine
University of California, San Diego

Michael Kaback, M.D.
Associate Professor of Pediatrics
UCLA School of Medicine

Miss Crissola Knudsen, Director
Loma Prieta Regional Center
San Jose

David R. Levy, M.D., M.P.H.
North Bay Regional Center
Napa

David Rimoin, M.D.
Department of Medical Genetic
Harbor General Hospital
Torrance

George S. Roche, Ph.D., Member
State Developmental Disabilities
Planning & Advisory Council
Sacramento

Mary Salocks
Los Altos

Miss Mary Lee Schuster
Department of Social Welfare
Sacramento

Nancy Shinno, M.D.
University of Southern California
Medical School
Los Angeles

Phyllis Smith, Chairman
California Hospital Commission
Encino

Robert Sparkes, M.D.
Department of Medicine – UCLA

H. M. Sterling, M.D.
University of California
Davis Medical School

Sandy Udovch
El Toro

Diane Wideryaski, M.S.W.
Orange County Regional Center

Howard Wolfinger, Jr., M.D.
Children's Hospital and Health Center
San Diego

LATER PREGNANCY AND DELIVERY
GROUP 1

Albert Fremont, M.D., Moderator
Santa Clara Valley Medical Center
Jean Clark, R.N., Recorder
Redding, California

Ms. Marian Baer, M.S., Director
for Training in Nutrition
University Affiliated Program
Children's Hospital Los Angeles
Los Angeles

William Bucher, M.D.
Children's Hospital Los Angeles
Los Angeles

Evis Coda, M.D.
Medical Director
Kennedy Regional Center

Jim Dobson, Ph.D.
Children's Hospital of Los Angeles
Los Angeles

Mr. James Fossum, Chief
Community Services Section
Department of Health
Sacramento

Mrs. Ruth Frantz, Chairman
Area Board III
Nevada City

Harry Fryer, M.D.
San Luis Obispo Medical Clinic
San Luis Obispo

Isabelle Gonthier
State Department of Rehabilitation
Sacramento

Mr. William T. Gray, Director
North Coast Regional Center
Ukiah

Doris Harris, M.D.
Los Angeles County Health Department
Los Angeles

Margaret Ann Inman
Providence Speech Clinic
Orange

Glenn Koford
Medical Director
Sonoma State Hospital

Bob Lemmon, Ed.D.
California State College
Fullerton

Mr. William Long, Chief
MR Hospital Section
Department of Health
Sacramento

Dr. William McCord
Regional Center for the MR
Children's Health Center
San Diego

Frank McNeese
Kern County Regional Center
Bakersfield

Mr. Don McNeff
Orange County
Department of Education

Raymond M. Peterson, M.D.
Medical Director
Regional Center for the
Mentally Retarded, San Diego

Dr. Peter Scharf
Professor of Social Ecology
University of California, Irvine

Mrs. Earlene Scharping
Department of Pediatrics
University of California, Irvine

Marilyn Simms
Tri-Counties Regional Center
Camarillo

William K. Smith
Administrative Director
Tri-Counties Regional Center
Santa Barbara

Kathy Ursin, Program Manager
Developmental Disabilities Program
Department of Rehabilitation
Sacramento

Nita Waite, Executive Director
United Cerebral Palsy Association of
Orange County

Ms. Doreen Wysocki
Tehama County Mental Health
Red Bluff

LATER PREGNANCY AND DELIVERY
GROUP 2

Ernest W. Page, M.D., Moderator
UC—San Francisco
Ruth Gormsen, M.S.W., Recorder
Social Service Department—Orange County Medical Center

Ms. Vickie Avidiya
San Jose Mercury
San Jose

Robert Boughn
Harbor Regional Center
Torrance

Ms. Kari Donahue
Program Director
Fairview State Hospital
Costa Mesa

Francis Durkin
Children's Hospital of Los Angeles
Los Angeles

Charles B. Fletcher, M.D.
Ventura

John G. Freeman, M.D.
Medical Director
Stockton State Hospital
Stockton

Ms. Gladys Gleason
Assistant Director
Speach & Language Development Center
Anaheim

Louis Gluck, M.D., Chairman
Area Board XIII
San Diego

Margaret Huelskamp, M.D.
Director of Medical Services
San Jose

Mrs. Lois Lindt
Executive Secretary
Area Board IX
Santa Barbara

Abraham S. Linn, M.D.
Medical Director
Napa State Hospital

Phyllis Mathy
Association for Retarded Children
San Diego

Irene Matousek, R.N.
University of Southern California
School of Medicine
Los Angeles

Charles McKean, M.D.
Chief, Research Unit
Sonoma State Hospital

John H. Menkes, M.D.
Department of Pediatrics — UCLA

Ms. Pauline Park
Colton

Don Piper, M.D.
Chief, Medical Services
Sacramento Alta California
Regional Center

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Golden Gate Regional Center
San Francisco

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Esmond Smith, M.D., Chief
Crippled Children Services
Sacramento

Dr. William Smitheran
Coordinator of Counseling
and Guidance Garden Grove

Denise Sofka
Developmental Disabilities Program
Department of Health
Sacramento

Irving Stone, Litt.D.
Fairview State Hospital
Costa Mesa

Luella Thornton
State Department of Health
Sacramento

INFANT AND YOUNG CHILD
GROUP 1

Allan Oglesby, M.D., Moderator
UC–Berkeley School of Public Health
Joan Boyd, P.H.N., P.N.P., Recorder
UC–San Francisco

Ms. Aleen Agranowitz
Speech & Language Development Center
Anaheim

Julia Arriaza, P.H.N.
Department of Pediatrics
University of California
Irvine

Arnold Binder, Ph.D.
Professor
Irvine

William M. Clover, M.D.
Medical Director
Pacific State Hospital – Pomona

Ray Darby, Superintendent
Shasta County Schools
Redding

Eugene Earl, M.D.
Shasta General Hospital
Redding

Mr. Nathan Edwards
Area Board VIII Chairman
Fresno

Ms. Adrienne Hunt, P.H.N.
Public Health Nursing Office
San Jose

Dorothy Johns
School Nursing Program of Siskiyou
Yreka

George Jones, DDS
Oroville

Harry Jones, M.D.
Medical Director
Camarillo State Hospital

Dr. Marjorie Keely
Fresno

C. Seibert Kinsell, M.D.
Children's Medical Clinic
Santa Barbara

Kathleen Lange
Nurse Consultant
Central Valley Regional Center
Fresno

Mrs. Jean Lasswell, M.S.W.
Orange County Medical Center

Jerome Mednick, M.D.
Children's Hospital San Francisco

Telford Moore, Ph.D.
Riverside

Thomas Nelson, M.D.
Department of Pediatrics
University of California
Irvine

Betsy Phoenix, R.N.
Nursing Coordinator
Orange

Mr. Vince Sternitzke
Program Director
Fairview State Hospital
Costa Mesa

Ann Teborg, M.D.
Casa Colina Hospital
Pomona

Anthony Toto, M.D.
Medical Director
Fairview State Hospital
Costa Mesa

Richard Umansky, M.D.
Children's Hospital Medical Center
Oakland

Miss Marie Wacht
Golden Gate Regional Center
San Francisco

Mr. Jerry Williams
Chief Counselor
North Coast Regional Center
Ukiah

INFANT AND YOUNG CHILD
GROUP 2
Joan Meisel, Ph.D., Moderator
Atypical Infant Development Program–Kentfield, California
Lincoln Shumate, M.D., Recorder
Fairview State Hospital

Mrs. Freda Arnold
Supervising School Nurse
Garden Grove

David Bilovsky, Ph.D., Director
Training Center in Mental Retardation
California State University–LA

Dr. Shanon Christiansen
Chabot Junior College
Hayward

Fred Coughlin
School Psychologist/Principal
Casa Blanca School
Riverside

Dr. Edith Dowley, Director
Bing Nursery School
Stanford University
Stanford

Judy Ebbin
Los Angeles

Dr. Clara Lee Edgar
Pacific State Hospital
Pomona

Mr. Robert Edwards, Director
Inland Counties Regional Center
San Bernardino

Lucille Grothe, M.S.W., Director
Child Welfare Service
Santa Ana

Mary Lou Hickman, M.D.
Central Valley Regional Center
Fresno

Mrs. Martha Hislop
HEW Region IX
San Francisco

Joan Honeycutt
Greeley Special Education Center
Orange

Mrs. Betts Jensen
Executive Director
California Epilepsy Society

Mr. Con Leatherman
Orange County Department of Education

Ms. Mary Jane Lewis
Ontario

Gerald I. Lubin, M.D.
University Affiliated Program
Children's Hospital Los Angeles

Dr. James Magary
University Affiliated Facilities
Children's Hospital of Los Angeles

Ivy Mooring, M.D.
Center for Training in
Community Psychiatry
Los Angeles

John Parker
Field Representative
State Easter Seal Society
Chico

Mrs. Carol Pike
South Laguna

Mrs. Georgiana Rodiger
Pasadena

Cliff Shryork
Department of Education
Sacramento

Margaret Steward, Ph.D.
Assistant Professor of
Child Psychiatry
Davis

Dr. Annette Tessier
Department of Special Education
California State University
Los Angeles

Jacqueline Thomas, M.S.W.
Division of Adoptions
Orange County Health Department

Professor Eleanor Wynne
Supervisor of Teaching
Department of Social Sciences
Irving

ACKNOWLEDGEMENTS

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State Developmental Disabilities Planning & Advisory Council –

John P. Morris, M.D., Chairman
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Mary Lee Schuster
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H. David Sokoloff
Mrs. Gwendolyn Stephens

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Rose Jenkins, M.D.
George S. Roche, Ph.D.
H. M. Sterling, M.D.
Robert E. Carrel, M.D.
Mary Lou Hickman, M.D.
John P. Morris, M.D.
Mary Fenley, R.N., F.N.P.
Kenneth Dumars, M.D.
Dale Thorsted
George Cunningham, M.D.

SPECIAL ACKNOWLEDGEMENTS

Office of Developmental Disabilities Staff

Allan D. Toedter
Holly Kensler
Karen Barlupe

Isabelle McDaniels

Conference Technical Consultant
Tadashi Mayeda

University of California

Chancellor Daniel G. Aldridge, Jr., Ph.D.
Kenneth Dumars, M.D.

Social arrangements

John Wayne
Mr. & Mrs. William Stephens
Max Shaffer

Conference photographer

Stephen M. Shaffer